MARYLAND COMPREHENSIVE CANCER PLAN
BREAST CANCER SUBCOMMITTEE
MINUTES OF THE JUNE 11, 2002 MEETING

Attendance:
Kathy Helzlsouer, MD, MHS, Johns Hopkins Bloomberg School of Public Health -Committee Chair
Abby Karlsen - Susan G. Komen Breast Cancer Foundation, Maryland Affiliate
Franny Lerner - Chase Brexton Health Center
Eric Whitacre, MD - The Breast Center at Mercy Hospital
Lorraine Tafra, MD - Anne Arundel Medical Center
Kathy Cupertino
Stanley Watkins, MD - Annapolis Medical Specialists
Renee Royak-Schaler, PhD - University of Maryland School of Medicine
Jacqueline Chambers - Sisters Surviving
Marsha Oakley " Arm-in-Arm, The Breast Center at Mercy Hospital
Stephanie Seipp " MedChi
Susan Bauman-Steuart " American Cancer Society
Joan Fell " Y-Me of the Cumberland Valley
Sunny England " Y-Me of the Cumberland Valley
Marc Heyison " Men Against Breast Cancer

DHMH Staff:
Donna Gugel - Breast and Cervical Cancer Screening Program (BCCP) Director
Kate Shockley - Comprehensive Cancer Control Coordinator
Toni Brafa-Fooksman - BCCP Coalition Coordinator
Marsha Bienia - Director, Center for Cancer Surveillance and Control

MEETING SUMMARY
Town Hall Meetings " Kate Shockley.

- There will be seven town hall meetings for the public to give input for the cancer plan. Committee members are invited to attend the meetings.
- Meetings will be held in Prince Georges, Anne Arundel, Charles, Montgomery, Washington, and Talbot Counties and Baltimore City, starting July 16th and ending August 8th. There will be teleconference sites in Salisbury and LaVale. Dates and locations will be posted on the web site (www.MarylandCancerPlan.org) when they are finalized.
- Participants will be given three questions to help focus their testimony:
    1) In your opinion, what are the most important cancer issues in your community?
    2) Within your community, what are the primary barriers to accessing cancer prevention, education, screening, and treatment programs
    3) What suggestions do you have for programs, partnerships, or services that could be created in your community to address the issues and barriers identified in questions 1 and 2.
- UMBC is coordinating the meetings. In addition to getting a copy of the minutes of individual meetings, committee members will receive a summary of the discussions related to

breast cancer.

- Please help publicize these meetings.

Existing Programs

Susan G. Komen Breast Cancer Foundation – Abby Karlsen

- The Susan G. Komen Breast Cancer Foundation is dedicated to the eradication of breast cancer as a life-threatening disease by advancing research, education, screening, and treatment. It is the largest private funder of breast cancer research in the United States.
- Headquartered in Texas, there are 115 affiliates in the United States and three international chapters.
- It is a grant-making and educational foundation, not a service provider.
- The Maryland Affiliate awards grants to community groups throughout the state, with the exception of Montgomery and Prince Georges Counties (which can apply to the national office for community grants).
- The Maryland Affiliate raises money through various activities including the Race for the Cure.
- The Maryland Affiliate does an annual needs assessment prior to releasing its RFP. Grants addressing the identified needs are considered for awards. Awards are made in the early spring. The RFP for 2003 should be available July 15, 2002.
- In addition to awarding grants, the Maryland affiliate sponsors an annual educational symposium, publishes a resource guide for breast cancer patients, publishes a biannual newsletter, participates in health fairs, makes referrals to various resources, sponsors an annual grant writing workshop and other educational programs.
- Komen has some materials that are targeted to African American women. They also publish some materials in Spanish. Abby is not aware of any listing of breast cancer resources for African American women..
- Chase Brexton mentioned that they have tried to use their Komen grants as seed money to apply for larger grants from other foundations, but have not been successful. This is partially due to issues of having to work with the Baltimore City Health Department to provide screening services. (Effective July 1, 1002 the BCCP screening for Baltimore City residents will be done through MedStar at Harbor and Union Memorial Hospitals.)

American Cancer Society – Susan Bauman-Steuart

- The primary focus of the American Cancer Society is prevention programs. They also sponsor research and patient services programs, publish numerous brochures, give work site presentations on cancer prevention, provide speakers for community events, sponsor support groups (I Can Cope and Cancer Survivors Network), provide transportation to appointments for cancer treatment (Road to Recovery), and have government relations and advocacy programs. Nationally they have issued a challenge to reduce cancer morbidity by 25% and incidence by 15% by 2015
- ACS publishes Cancer Facts and Figures annually. There are separate Cancer Facts and Figures for: Hispanics, African Americans, Mid-Atlantic Region, and Breast Cancer.
- Maryland is part of the Mid-Atlantic Region of the ACS. This division also includes

Delaware, Washington, D.C., Virginia, and West Virginia.

- Breast cancer is one of ACS's target cancers. Their goal is to increase the number of women receiving annual mammograms to 75% and to provide services to 65% of all women with newly diagnosed breast cancers by 2007.
- Breast cancer programs include:
  1) The ACS Tell-A-Friend program recruits and trains women to call friends and relatives to encourage them to have a mammogram. Local ACS offices are working to implement this program. In the Baltimore area the goal is to contact 8000 women.
  2) A community breast health education program
  3) Breast Cancer newsletter
  4) Reach to Recovery – support for newly diagnosed breast cancer patients
  5) Mothers Day cards
  6) TLC Catalogue – includes wigs and prosthesis
- Locally, ACS is working to expand the Road to Recovery program. They hope to be able to provide transportation to medical appointments and for cancer screening and follow-up services, in addition to appointments for cancer treatment.

DHMH – Breast and Cervical Cancer Program (BCCP) – Donna Gugel
Maryland Diagnosis and Treatment Program

- In 1990 Congress passed the Breast and Cervical Cancer Mortality Act which provided money to the Centers for Disease Control to establish the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Maryland is one of the original 12 programs to be funded. Programs exist in all 50 states, 6 U.S. territories, and 14 American Indian/ Alaska Native organizations. Breast and cervical cancer screening services (CBE, mammogram and Pap smear) are available to low income, uninsured (or underinsured) women 40-65 years of age.
  - In addition to screening services BCCP can pay for diagnostic follow-up (diagnostic mammograms, breast ultrasound, and colposcopy), physician referrals and surgical consultations, and case management. States must provide assurances that all women enrolled in BCCP and diagnosed with breast or cervical cancer will receive medical treatment.
  - In 1997 the Maryland legislature passed a bill that provides state funding to supplement the CDC program. This money is primarily used to screen women 40-49 years of age.
  - Women with Medicare Part B, HMOs and PPOs are ineligible for BCCP.
  - During 2001 BCCP provided 12610 mammograms to Maryland women.
  - Maryland provides a higher percentage of mammograms to African American and Hispanic women than are in the general population. Thirty-six per cent of first visit mammograms are given to African American women. Their rescreen rate is 31%.
  - The number of Asia and Pacific Islander enrolling in BCCP is increasing
  - DHMH administers the state and CDC grants. Screening programs are available through the local health departments in all 23 counties. Effective July 1, 2002 MedStar will be the contractor for the Baltimore City program.
  - The BCCP budget is approximately seven million dollars.

    - Staffing in each jurisdiction is proportional to the number of patients enrolled. All jurisdictions have a program coordinator, at least some outreach/secretarial support. To screen more women most counties would need additional funding and staff.
    - Funding is allocated to the jurisdictions, based on the number of patients enrolled in the program and estimates of the number of county residents who are program eligible.
- The Diagnosis and Treatment Program provides diagnostic and treatment services for women with suspected breast or cervical cancer. The program is open to Maryland residents of any age, who meet income guidelines (similar to, but not the same as for BCCP), and are uninsured or underinsured. A doctor must certify that the patient needs a diagnostic work-up or treatment. Women do not have to be screened through BCCP in order to participate in the program.
- The Breast and Cervical Cancer Treatment Act, passed by Congress in 2000, allows states to enroll BCCP patients who have been diagnosed with either breast or cervical cancer in a special Medical Assistance program. Maryland began implementing this program on April 1, 2002. Women in this program are eligible for full Medical Assistance while they are undergoing treatment for breast(including Tamoxifen) or cervical cancer.

Committee members made several comments:

- In Washington County they have found that many women have insurance, but that their deductibles are very high. Y-Me of the Cumberland Valley works with the county health department to pay for screening for women who are not BCCP eligible. Washington County recently received a Make a Difference grant from Komen to provide screening services for low-income women in rural areas.
- BCCP and the Diagnosis and Treatment programs should actively solicit more providers.
- DHMH should make providers aware of these programs. Quarterly training in different regions of the state for providers, social workers, etc. to make them aware of these programs was suggested.
- Committee members wanted to know if there is any pressure in Congress to decrease funding for the CDC program? (Not at the present time.)
- One way to increase screening is to mandate coverage outside of any insurance deductible. Note: In 1993 Maryland passed a law mandating coverage for screening mammography. However, because of ERISA many insurance programs are exempt from this law. About 30 % of the health insurance policies written in Maryland are actually required to provide mammography coverage under this law. It was suggested that the state advertise the names of the insurance companies that do not provide screening services.
- The Maryland legislature passed HB1267 in 2001. This bill authorized the Maryland Diagnosis and Treatment Program to pay for breast reconstruction. However, the law does not require the inclusion of funding for the specified program/service in the state budget. Without additional funding the Reimbursement for Breast and Cervical Cancer Diagnosis and Treatment Program can not pay for breast reconstruction.

Maryland Cancer Registry – Kathy Helzlsouer, MD, MPH

Dr. Helzlsouer distributed cancer registry data pertaining to breast cancer in Maryland. This information was obtained from the Maryland Cancer Registry. The data is reported by region (Baltimore Metro, Eastern Shore, National Capital, Southern, and Northwest). Included is data on the tumor size, type of treatment, breast reconstruction, tumor stage, patient age, and the length of time between diagnosis and treatment. Anyone wanting additional data should contact Donna Gugel. Stacey Neloms, Director of the Maryland Cancer Registry, will attend the next meeting to discuss registry data.

- The law requires that all cases of cancer be reported. In most cases, the tumor registrars at the hospitals report the data. Hospital data is probably the best resource because it is more likely to be complete.
- The suggestion was made that the registry collect information on estrogen receptor status.
- It was suggested that the State adopt a standard reporting form that pathologists could use. The American College of Surgeons has developed a questionnaire that can be used as a reporting form.

General Comments / Priority Issues to be Addressed/Recommendations

Community/Patient Education:

- Need educational programs that are culturally sensitive. Materials are needed for deaf women.
- Need a research- based approach to cultural sensitivity.
- Different approaches are needed for different communities.
- Attention needs to be paid to how materials are translated into different languages. The same word/phrase may mean different things to people from different countries even though the language is the same.
- Breast cancer is a family issue. Support/educational programs are needed for family members.
- Need funding for community outreach workers.
- Need something new and attention grabbing.
- Educational and support programs for long term survivors to improve quality of life.
- Design programs to fit the needs of the community.
- Clarify for consumers what insurance companies provide or don't provide.

Physician education:

- Maryland law requires that physicians discuss alternative treatments for breast cancer with their patients and give them a booklet about treatment options. This is not always being done. DHMH receives a list of physicians who are newly licensed to practice in Maryland each month and sends them a letter about this law. Not all doctors starting practices in the state are on this list. All surgeons and oncologists in the state should be sent a letter advising them about the new alternative treatment booklet. This is a law without enforcement regulations.
- Make providers aware of existing programs.
- Education to increase the use of non-invasive diagnostic approaches.

Research issues:

- Look at sentinel node biopsy.
- Focus on non-invasive diagnostic approaches as opposed to open biopsies.

- Reoccurrence of breast cancer in women who have been on Tamoxifen for five or more years. It appears that Tamoxifen is metabolized differently in African American and Caucasian women.
- Integrate peer review research into screening programs.
- If we have increased screening rates among African American women, why are their tumors diagnosed at a later stage than for white women and why do younger women have larger tumors?
- Do we need other screening modalities for African American women?
- Need competitive research grants, not limited to the University of Maryland and Hopkins.
- Research on the influence of environmental factors on breast cancer.
- Why does Maryland continue to have one of the highest breast cancer mortality rates in the nation, despite high screening rates?
- Research into prevention programs.
- Treatment protocols for abnormalities found using virtual screening (scans).
- Look at the California model for use of tobacco funds for research.

Access to care:

- Recruit additional providers for BCCP and the Diagnosis and Treatment Programs
- Increased payment for mammography.
- Assistance with transportation to screening services and follow-up appointments
- Lower the age requirement for BCCP.
- BCCP requirements for participation are too restrictive.
- Increase access to education and early detection.
- Financial assistance for women with insurance with high deductibles and who fall into the gray areas.
- Need free/low cost screening services for high risk or symptomatic women who are less than forty years of age.
- Additional funding for screening and treatment.
- Need to overcome social and economic barriers to care. Low-income women have other issues that prevent them from getting screened.
- Increased availability of screening services.
- Increase mammography screening for African American women.
- Fill in the gaps for women who are ineligible for existing programs.
- All insurance companies should have to adhere to same standards and should have report cards issued by the insurance commissioner.
- Increase post-treatment access to quality of life resources, other health screenings and long-term survivorship issues.

Other issues:

- The committee would like to look at how CRF funds are spent and make recommendations for allocation of funds.
- The committee wanted to discuss whether or not the Maryland CRF program should fund research.

The literature review and summary page of committee identified objectives for Maryland to

decrease the burden of breast cancer and to decrease racial disparities were distributed.

Committee members were asked to review the literature and to come up with recommendations to discuss at the next meeting. Recommendations can be sent via e-mail to Toni Brafa-Fooksman at fooksmant@dhmh.state.md.us before the next meeting.

THE NEXT MEETING OF THE BREAST CANCER COMMITTEE WILL BE ON MONDAY, AUGUST 26, 2002 at 4:00 p.m.